

## General Assembly

Committee Bill No. 465

January Session, 2013

LCO No. 2957



Referred to Committee on PUBLIC HEALTH

Introduced by: (PH)

## AN ACT REQUIRING NEWBORN SCREENING FOR ADRENOLEUKODYSTROPHY.

Be it enacted by the Senate and House of Representatives in General Assembly convened:

- 1 Section 1. Subsection (a) of section 19a-55 of the general statutes is
- 2 repealed and the following is substituted in lieu thereof (Effective
- 3 *October 1, 2013*):
- 4 (a) The administrative officer or other person in charge of each
- 5 institution caring for newborn infants shall cause to have administered
- 6 to every such infant in its care an HIV-related test, as defined in section
- 7 19a-581, a test for phenylketonuria and other metabolic diseases,
- 8 hypothyroidism, galactosemia, sickle cell disease, maple syrup urine
- 9 disease, homocystinuria, biotinidase deficiency, congenital adrenal
- 10 hyperplasia, adrenoleukodystrophy and such other tests for inborn
- 11 errors of metabolism as shall be prescribed by the Department of
- 12 Public Health. The tests shall be administered as soon after birth as is
- 13 medically appropriate. If the mother has had an HIV-related test
- 14 pursuant to section 19a-90 or 19a-593, the person responsible for
- 15 testing under this section may omit an HIV-related test. The
- 16 Commissioner of Public Health shall (1) administer the newborn

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17 screening program, (2) direct persons identified through the screening 18 program to appropriate specialty centers for treatments, consistent 19 with any applicable confidentiality requirements, and (3) set the fees to 20 be charged to institutions to cover all expenses of the comprehensive 21 screening program including testing, tracking and treatment. The fees 22 to be charged pursuant to subdivision (3) of this subsection shall be set 23 at a minimum of fifty-six dollars. The Commissioner of Public Health 24 shall publish a list of all the abnormal conditions for which the 25 department screens newborns under the newborn screening program, 26 which shall include screening for amino acid disorders, organic acid 27 disorders and fatty acid oxidation disorders, including, but not limited 28 to, long-chain 3-hydroxyacyl CoA dehydrogenase (L-CHAD) and 29 medium-chain acyl-CoA dehydrogenase (MCAD).

| This act shal sections: | l take effect as follo | ows and | shall amend the following |
|-------------------------|------------------------|---------|---------------------------|
| Section 1               | October 1, 2013        |         | 19a-55(a)                 |

## Statement of Purpose:

To require that newborns be screened for adrenoleukodystrophy.

[Proposed deletions are enclosed in brackets. Proposed additions are indicated by underline, except that when the entire text of a bill or resolution or a section of a bill or resolution is new, it is not underlined.]

Co-Sponsors: SEN. FASANO, 34th Dist.

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